

Sussex Palliative and End of Life Care Needs Assessment 2025/26

Paediatric palliative care and end of life care for babies, children, and young people, and families

Key findings webinar

Ross Boseley

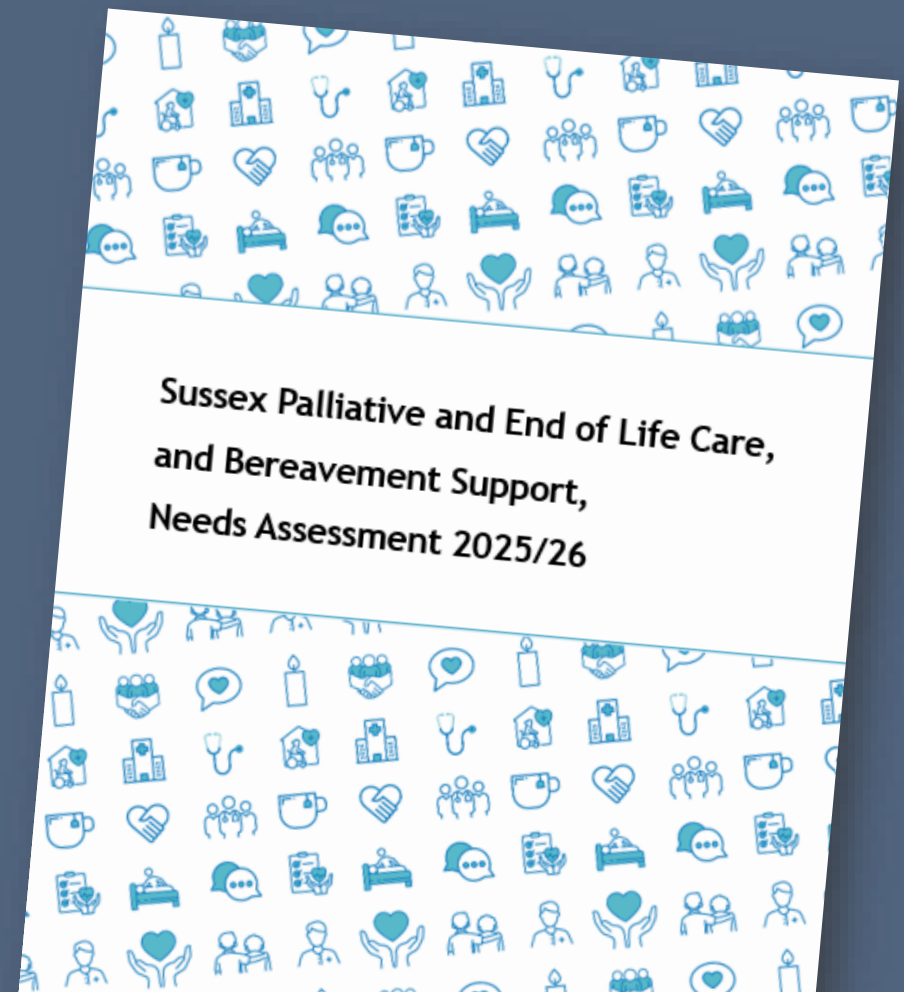
Health Improvement Principal

East Sussex County Council

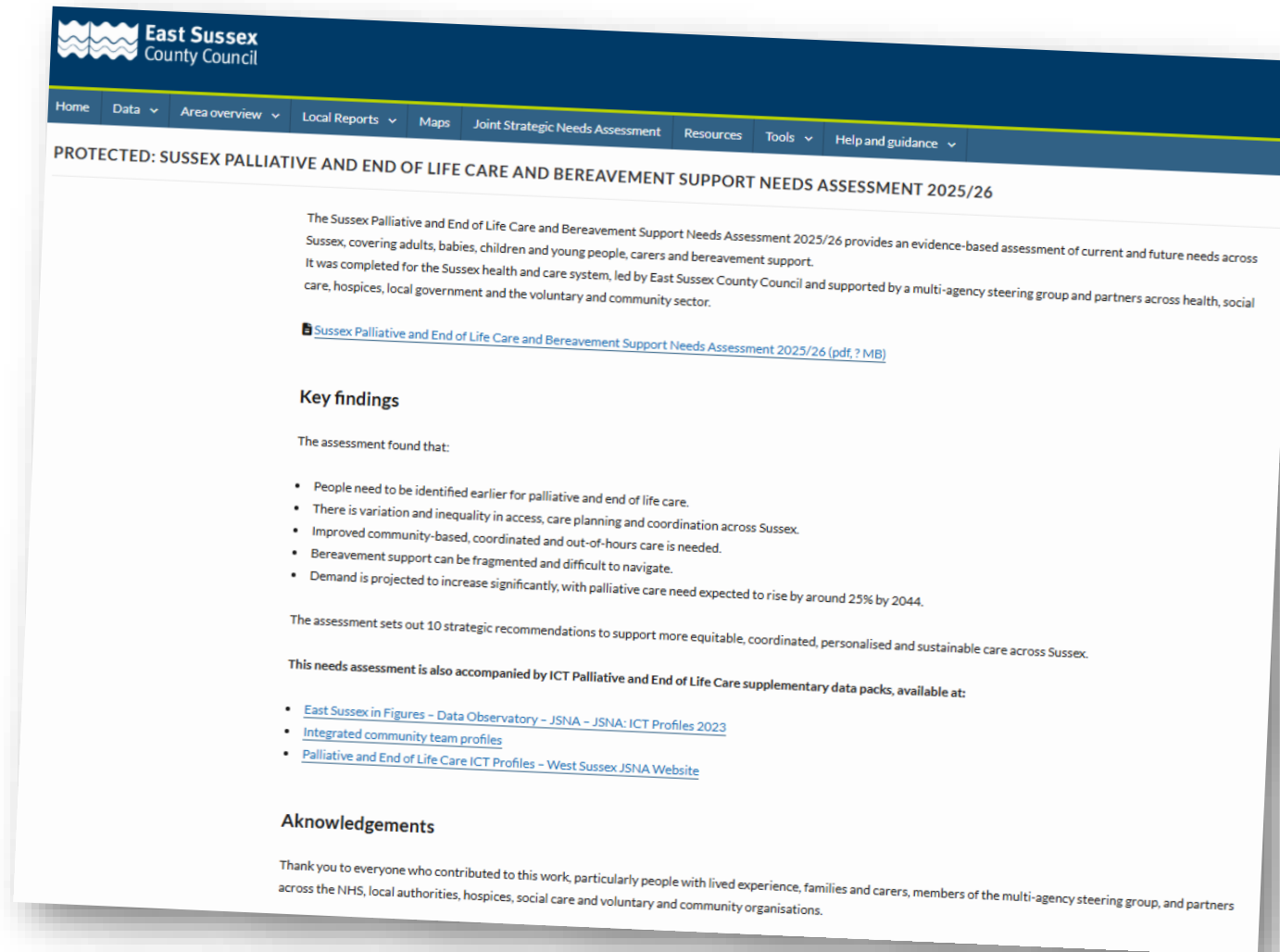
Faye Nel

Senior Commissioning Manager Palliative and End of Life Care

NHS Surrey and Sussex



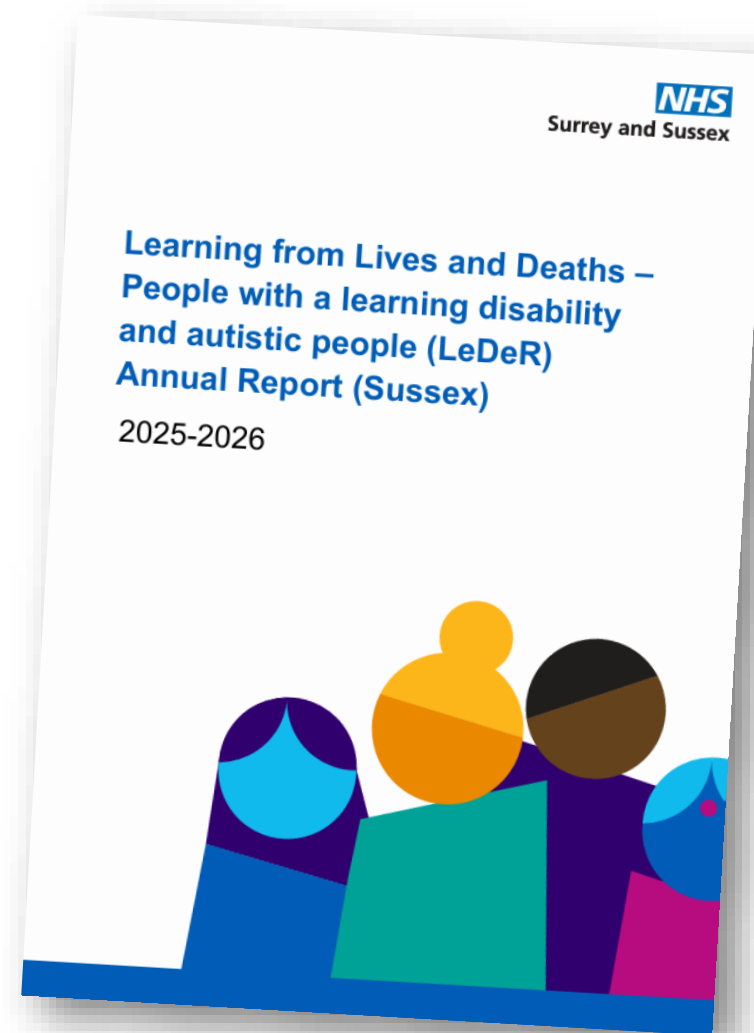
JSNA East Sussex web page



[JSNA: Sussex Palliative and End of Life Care and Bereavement Support Needs Assessment 2025/26](#)



[Child Death Review | ICB - Surrey and Sussex](#)



[Reports and Plans | ICB - Surrey and Sussex](#)

Celebrating compassionate care across Sussex

Acknowledging the people and partnerships supporting infants, children, young people and families at the end of life



Thank you to colleagues across the NHS, local authorities, hospices, social care, care providers, ambulance services, primary care, community services and the voluntary and community sector. The report recognises dedicated staff who deliver compassionate, person centred and coordinated care, often at the most difficult time in people's lives.

Children's hospice care

"Hospice services are proving excellent symptom management and EOLC care in hospices and own homes."

Children's hospice lead nurse

Partnership working

"Close working between Demelza, Chestnut Tree House and local children's community nursing services."

Community paediatric palliative care team lead

Choice of setting

"Joint up working, allowing patients to have the choice as to where they want to die - hospice, at home, hospital."

Family support respondent

Bereavement asset

"Our hospices have good bereavement support services."

Clinical lead nurse

Post death care

A local team reported post-bereavement care at home so a child can remain at home for 48 hours.

Workforce skill, kindness and commitment make dignity, comfort and choice possible many people and families across Sussex.

National context: need is rising and extending into adulthood

Prevalence and survival trends change the shape of paediatric palliative care

85,000+

CYP in England who could benefit from palliative care

32,975 → 86,625

CYP with life-limiting or life-threatening conditions, 2001/02 to 2017/18

26.7 → 66.4

Prevalence per 10,000 over the same period

921 → 3,075

Young people surviving to age 19

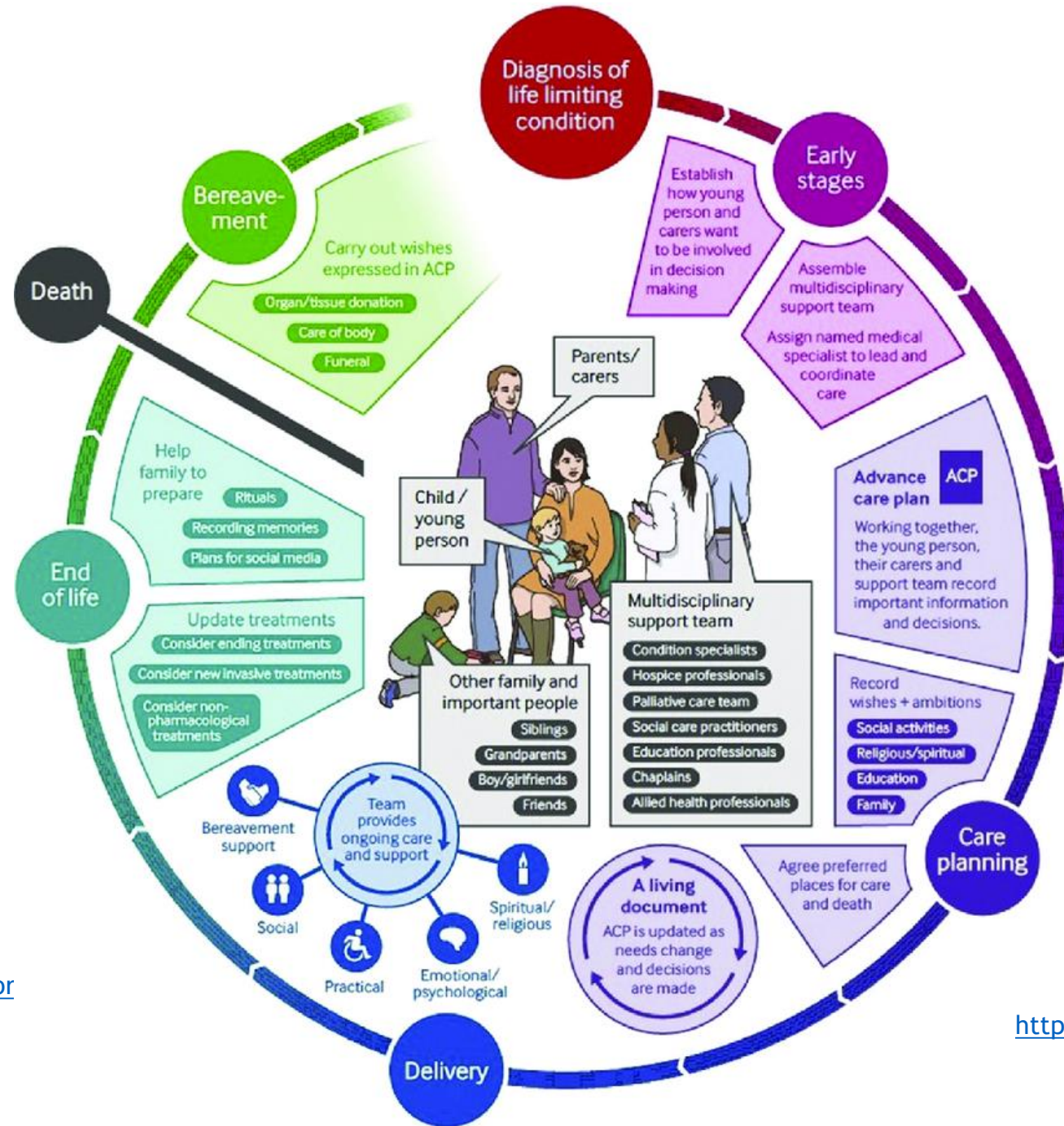
Longer illness trajectories require repeated assessment, respite, symptom management, family support and co-ordinated care over years, not only at the terminal phase.

Need is higher in deprived groups.

Services require an equitable model and a workforce prepared for complex, changing needs and transition into adult services.

Rising prevalence means sustained support, not simply more end-of-life episodes.

[Prevalence report.pdf](#) / togetherforshortlives.org.uk



Visual summary: End of life care for and young people

Sussex CYP Hospice Data

A substantial, predominantly community-based offer

Hospice care extends far beyond inpatient EoLC data from April 2022 to March 2025

20,093

care and support contacts

12,036

community nursing contacts

3,242

counselling contacts

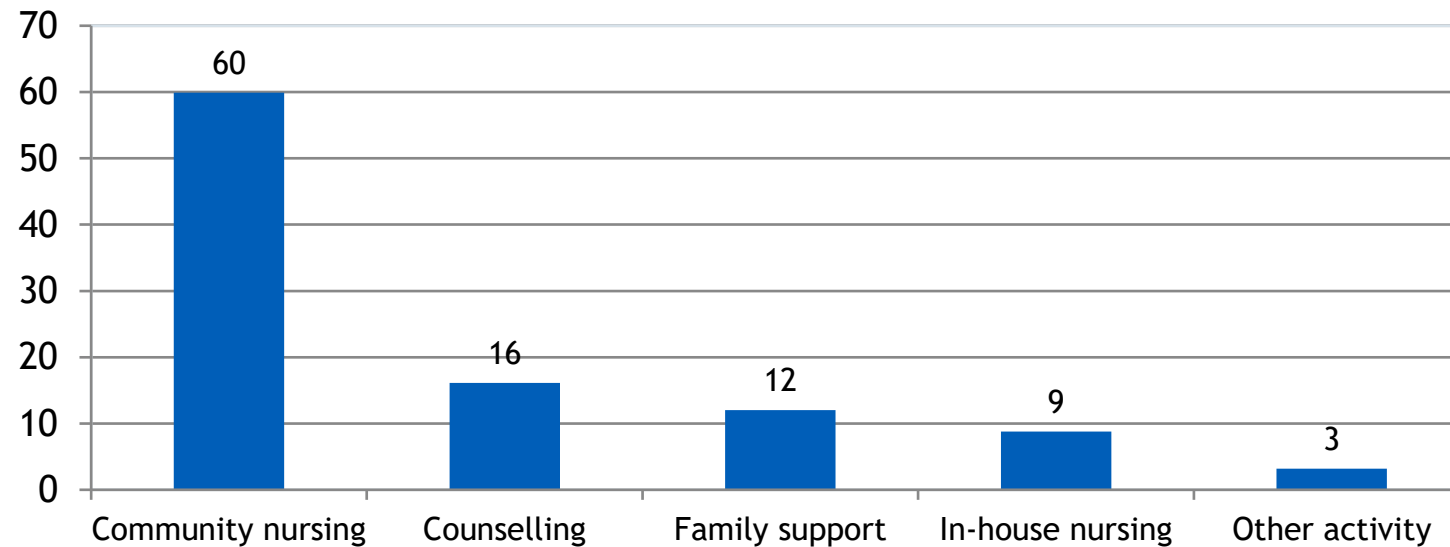
2,409

family support contacts

1,672

respite admissions

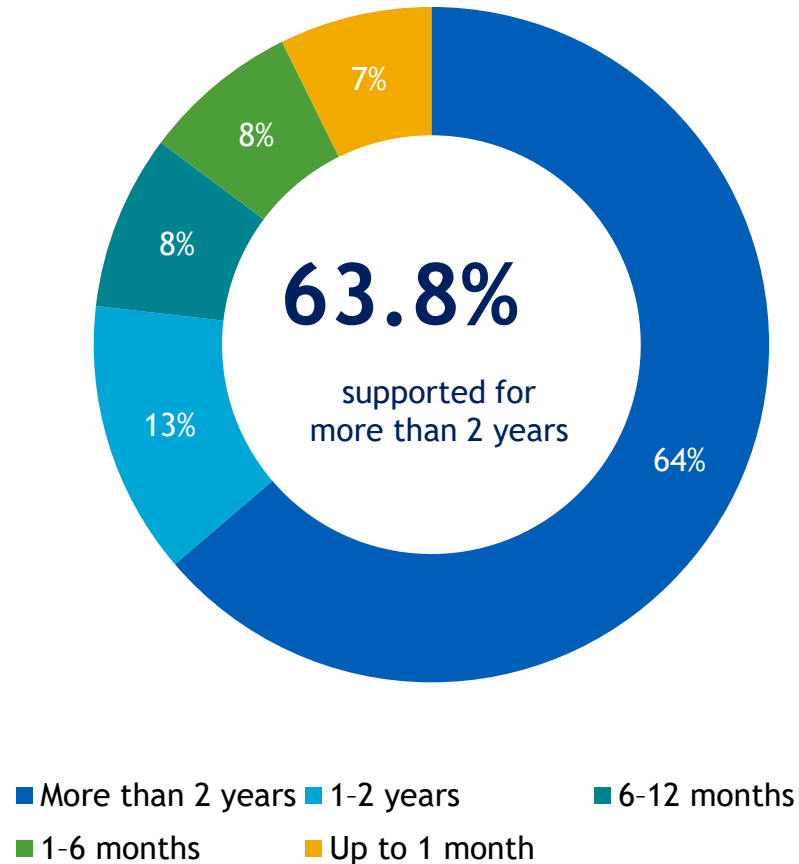
Share (%) of all hospice support activity, April 2022 to March 2025



Capacity planning must cover community nursing, counselling, family support and respite, not only beds.

Need is long-term, not confined to the final days

Most children are supported over prolonged and changing illness trajectories



550

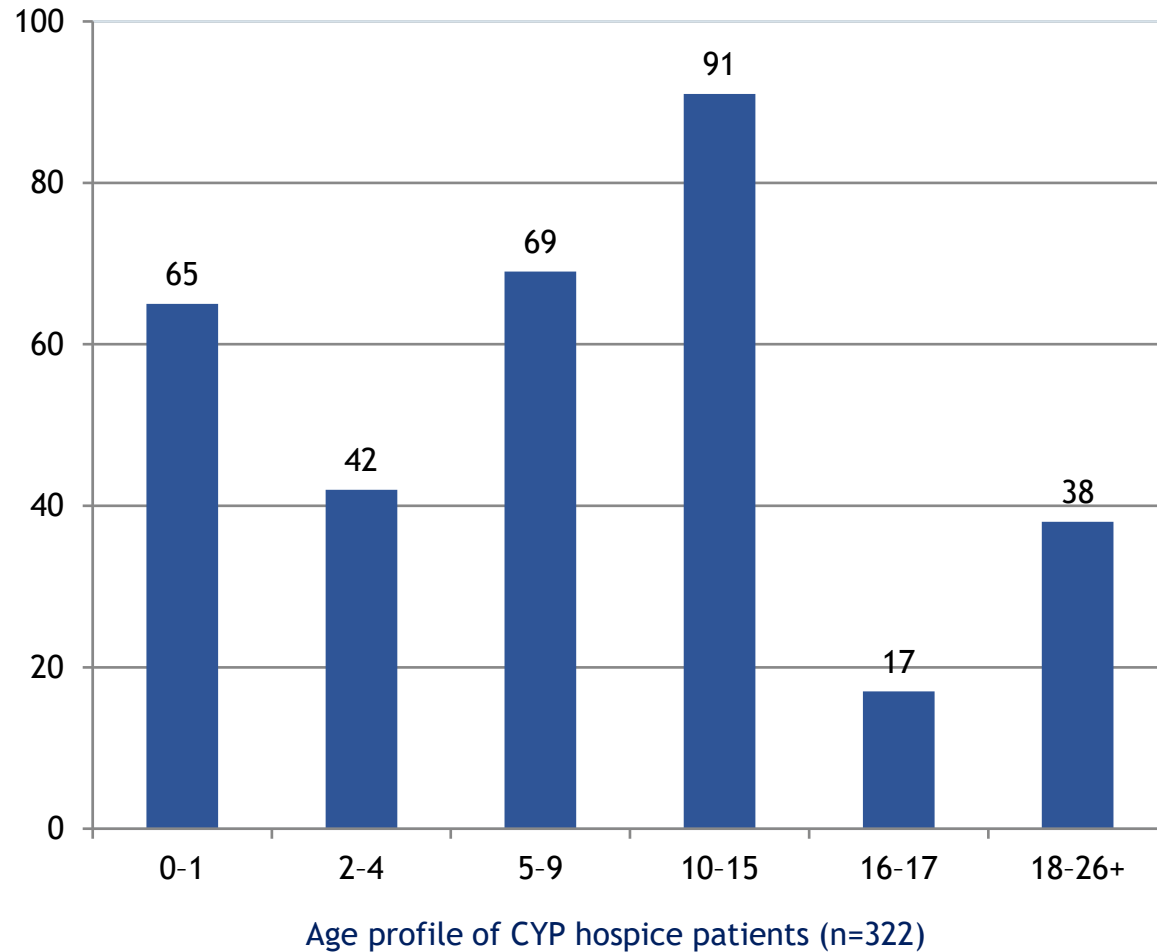
Patient and families recorded duration of hospice support data from April 2022 to March 2025

- Stable, sustained relationships with families
- Regular review as needs and prognosis change
- Respite and psychosocial support over years
- Workforce and funding models designed for continuity

Future demand will be driven by duration and complexity as much as by the number of deaths.

The population has complex needs across childhood and young adulthood

Transition age demand is visible within the hospice caseload



52% had multiple or complex conditions

38 patients were aged 18-26+

18% ethnicity not known or not stated

Commissioning needs strong transition pathways, complex-care capability and better equality data.

Hospices support care at death and continue with families afterwards

EoL activity is smaller in volume but high in intensity

35

deaths in hospice inpatient
units

49

deaths in the community
under hospice teams

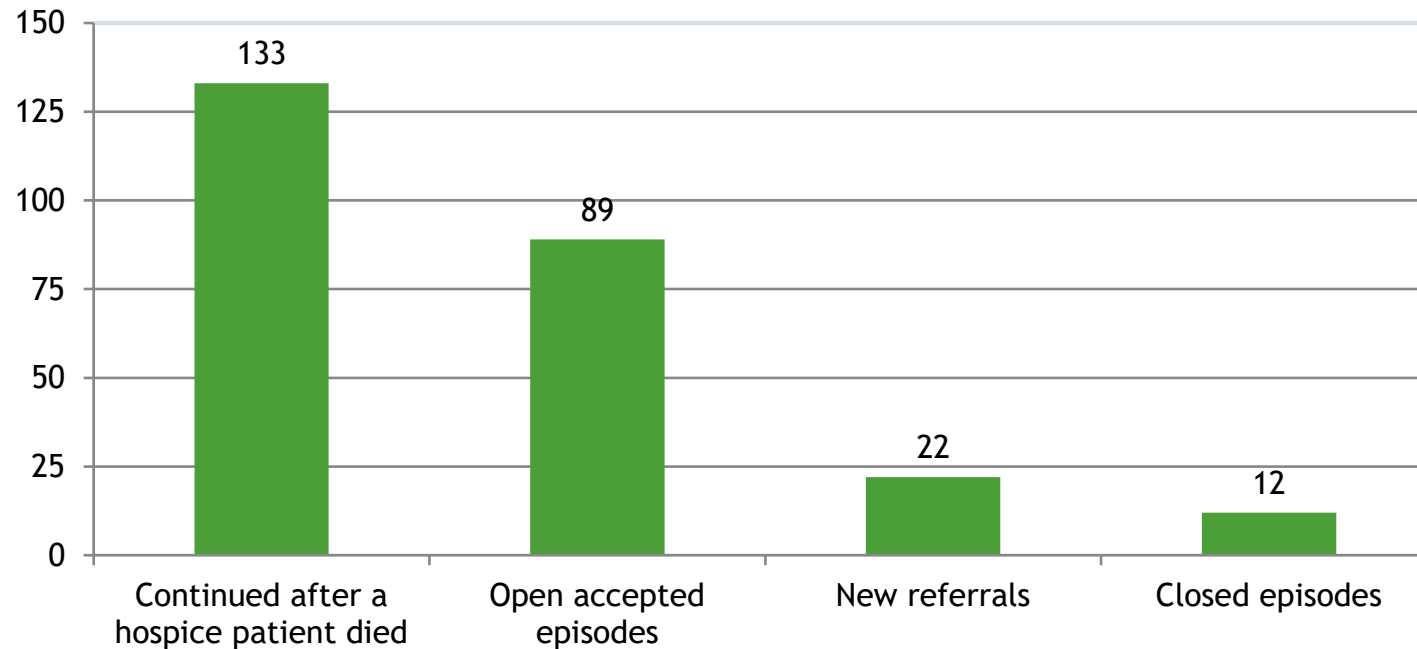
5.43 days

average inpatient stay before
death

392

people receiving
bereavement support

Bereavement support activity

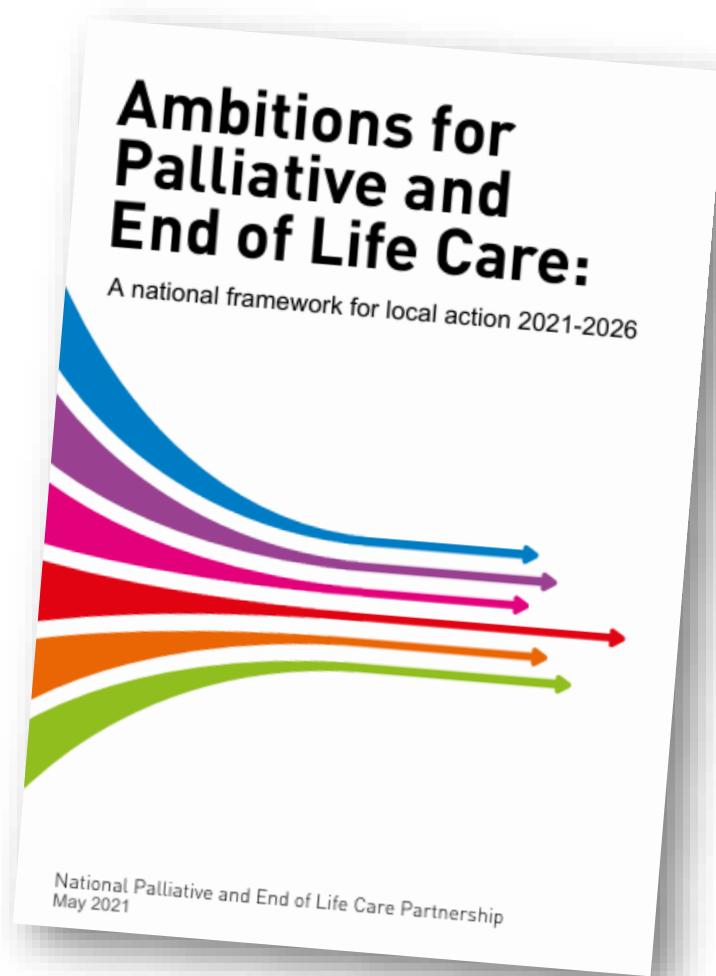


33

average contacts
per bereaved
child/family per
year

Bereavement care is a core, sustained and resource-intensive part of the pathway.

National Palliative and End of Life Care Partnership



01

Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03

Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04

Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

1 Each child is seen as an individual

Honest, timely conversations and care built around the child and family

82% cancer deaths with an ACP at death

33 life-limiting condition deaths reviewed, 2023-26

17/18 Children with life limiting conditions aged 4+: 17 had confirmed learning disability

WHAT IS WORKING WELL

- Many cancer families were supported to choose a preferred place of care and death.
- CDOP found child and family involvement in decision-making and advance care planning.
- Personalised care and meaningful experiences were created around individual needs.

WHAT NEEDS IMPROVEMENT

- Delayed palliative involvement recurred, linked to parental readiness or delayed recognition of deterioration.
- ACP and ReSPECT require regular review as needs change.
- Engage both parents, including non-resident or separated parents, and explain what to expect after death.

“Professionals should initiate timely and confident conversations about Advance Care Planning.”

CDOP

2 Each child gets fair access to care

Access should reflect need, not geography, diagnosis, disability or family circumstance

81% of children that died in Sussex have been classified as white



Significantly higher mortality rate in most deprived

(33%) Aged 4-17 who died with a confirmed learning disability in 2024/2

WHAT IS WORKING WELL

- East Sussex respondents described excellent hospice symptom management in hospices and homes.
- Close working was reported between children's hospices and community children's nursing.
- LeDeR uses focused reviews to examine inequalities.

WHAT NEEDS IMPROVEMENT

- Workforce feedback identified low referrals among some minority ethnic families and Gypsy, Roma and Traveller communities.
- CDOP found significant gaps in out-of-hours and community provision affecting preferred place of care and death.
- East Sussex-specific CDOP counts cannot be derived from the supplied Pan-Sussex files.

"We know that referrals are low for BAME families."

East Sussex PEOC workforce survey

3 Maximising comfort and wellbeing

Proactive symptom control, emotional support and care in the preferred setting

50% + cancer deaths
occurred at home

1/3 cancer deaths
occurred in hospice

CYP Cancer deaths in hospital involved pneumonia as a contributing factor in children with leukaemia

WHAT IS WORKING WELL

- CDOP identified well-developed and promptly implemented symptom-management plans.
- Many families valued compassionate, respectful and personalised care.
- East Sussex hospice respondents reported symptom management and end-of-life care in hospice and at home.

WHAT NEEDS IMPROVEMENT

- Community capacity and medicines access must reliably support comfort at home.
- Explain limitations of hospice settings before transfer to prevent distress.
- Ensure timely spiritual or religious support aligned with family beliefs and preferences after death.

“Hospice services are proving excellent symptom management and EOLC care in hospices and own homes.”

East Sussex hospice lead

4 Care is co-ordinated

The right help, information and response across acute, community, hospice and tertiary care

32% cancer cases with diagnostic delays

57% of delays involved brain tumours

24/7 specialist advice

WHAT IS WORKING WELL

- CDOP found effective multidisciplinary communication and seamless care in a number of cases.
- East Sussex respondents described close hospice, community nursing, GP and tertiary consultant links.
- Families could access specialist advice around the clock in reviewed cancer cases.

WHAT NEEDS IMPROVEMENT

- ACP documentation must be visible to the whole MDT, including ambulance services.
- Adult and paediatric oncology leadership and communication were sometimes unclear.
- Formalise equitable 24/7 advice, community response and clear leads rather than relying on goodwill.

“Limited hospice teams... mean that we work above and beyond hours to ensure the child and families have the services that they need.”

East Sussex team lead

5 All staff are prepared to care

Competent, confident and compassionate practice across every setting

595 people trained in Stop Look Care, 2024/25

202 professionals trained in Child Death Review training

392 Attended Safer Sleep for Babies and Coping with a Crying Baby

WHAT IS WORKING WELL

- CDOP recognised exceptional professional effort, often exceeding standard good care.
- LeDeR has translated review learning into training and accessible resources.
- East Sussex respondents recognised strong skills across hospice and community teams.

WHAT NEEDS IMPROVEMENT

- Build confidence in sensitive conversations, prognosis, deterioration and paediatric ACP.
- Improve skills for teenagers, transition and collaboration between adult and paediatric services.
- Apply reasonable adjustments and communication support for children with learning disabilities and autism.

“The facilitator was really knowledgeable and passionate about the topic of service improvement. The inclusion of people with learning disabilities in resources helped to reinforce the importance of the programme and the ethos of the programme. I learned lots of valuable information.”

Sussex LeDeR training feedback

5 Each community is prepared to help

Families, schools, VCSE and communities are informed and supported before and after death

WHAT IS WORKING WELL

- CDOP found effective emotional and bereavement support in reviewed cancer cases.
- Hospice responses described whole-family psychotherapeutic and post-bereavement support.
- LeDeR shares learning widely and works with VCSE and people with lived experience.

WHAT NEEDS IMPROVEMENT

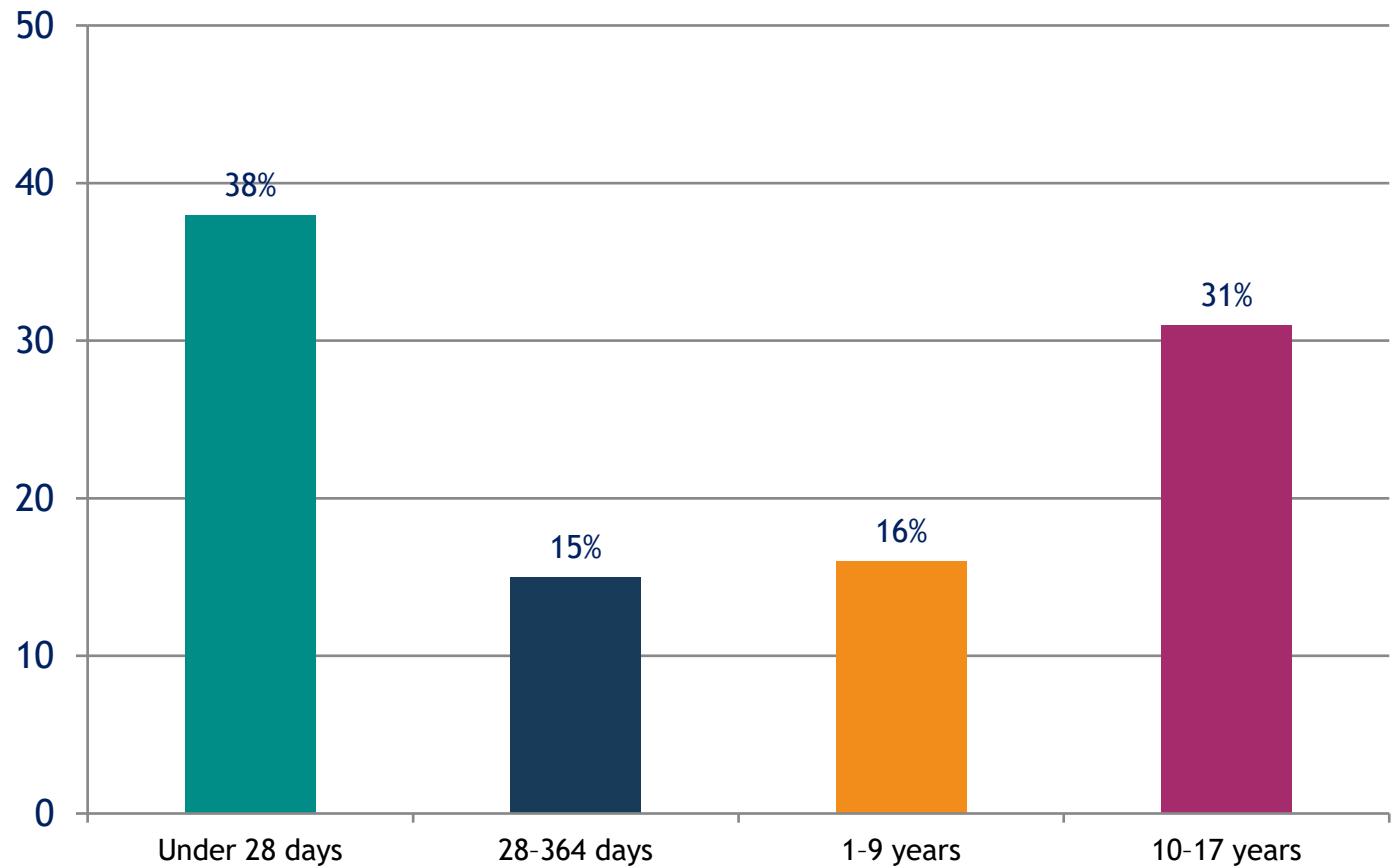
- Improve awareness of children's hospice services and earlier referral.
- Provide accessible, culturally sensitive and developmentally appropriate information on dying, death and bereavement.
- Strengthen sibling, family, faith and community support, including transition to adult services.

“Our organisation offers psychotherapeutic services for the whole family.”

East Sussex hospice lead

Age of infant and child deaths

Deaths notified to Sussex CDOP in 2024/25



53%

of deaths were among infants under one year

The largest difference from England was among 15-17-year-olds: 22% in Sussex compared with 11% nationally.

More than half of deaths occurred in the first year of life, while older teenagers formed a notable share.

Ethnicity and place of death

Ethnicity uses pooled five-year Sussex data; place of death relates to 2024/25 notifications

Ethnicity recorded

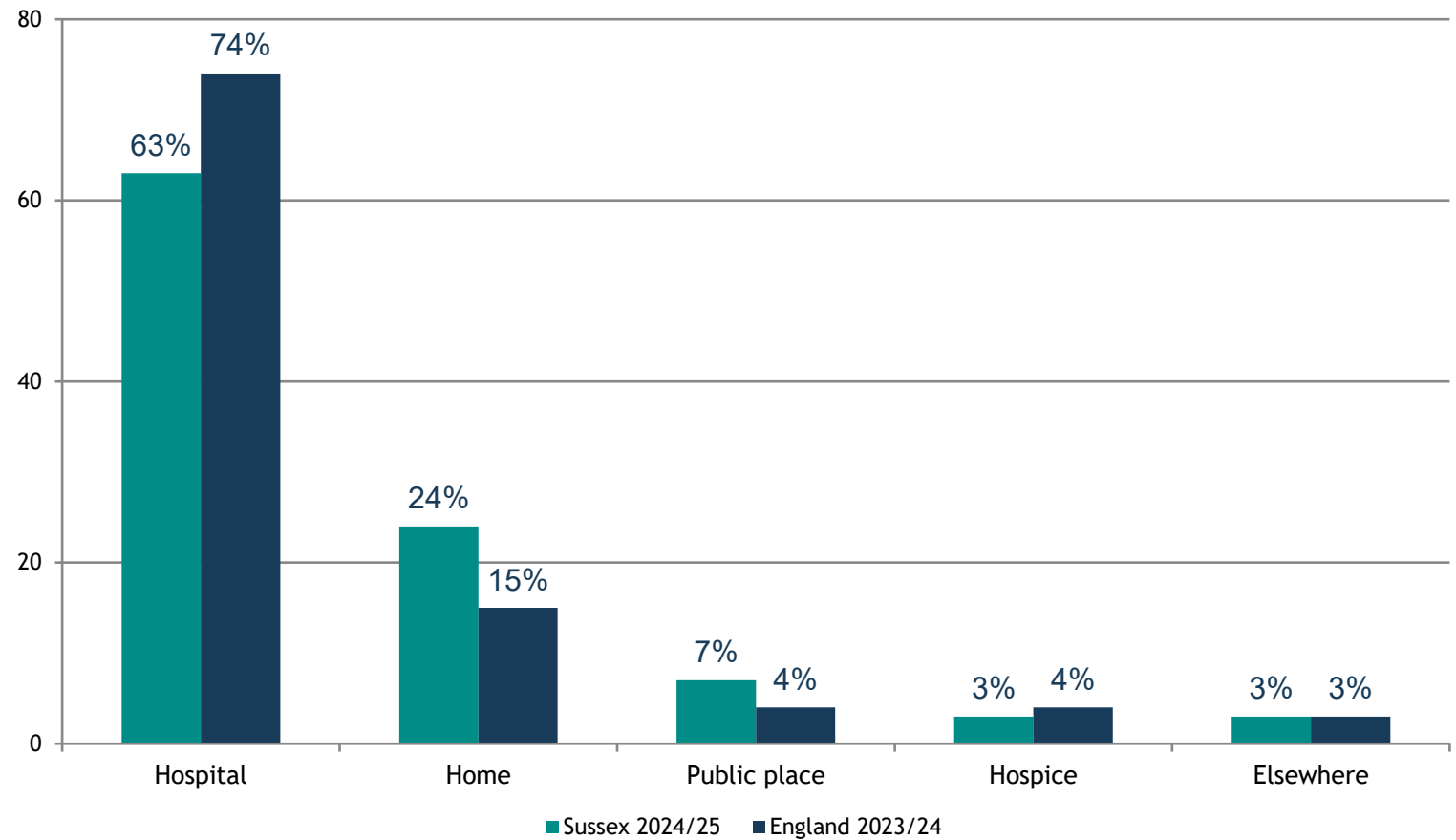
100%

of cases in each of the last four years

81%

classified as White in pooled Sussex data from the last five years

Small numbers mean the report does not draw further conclusions by ethnicity.



Most deaths occurred in hospital, but home and public place deaths were higher than England.

Bereavement support begins before and continues after death

Family-wide support is an integral part of the paediatric pathway

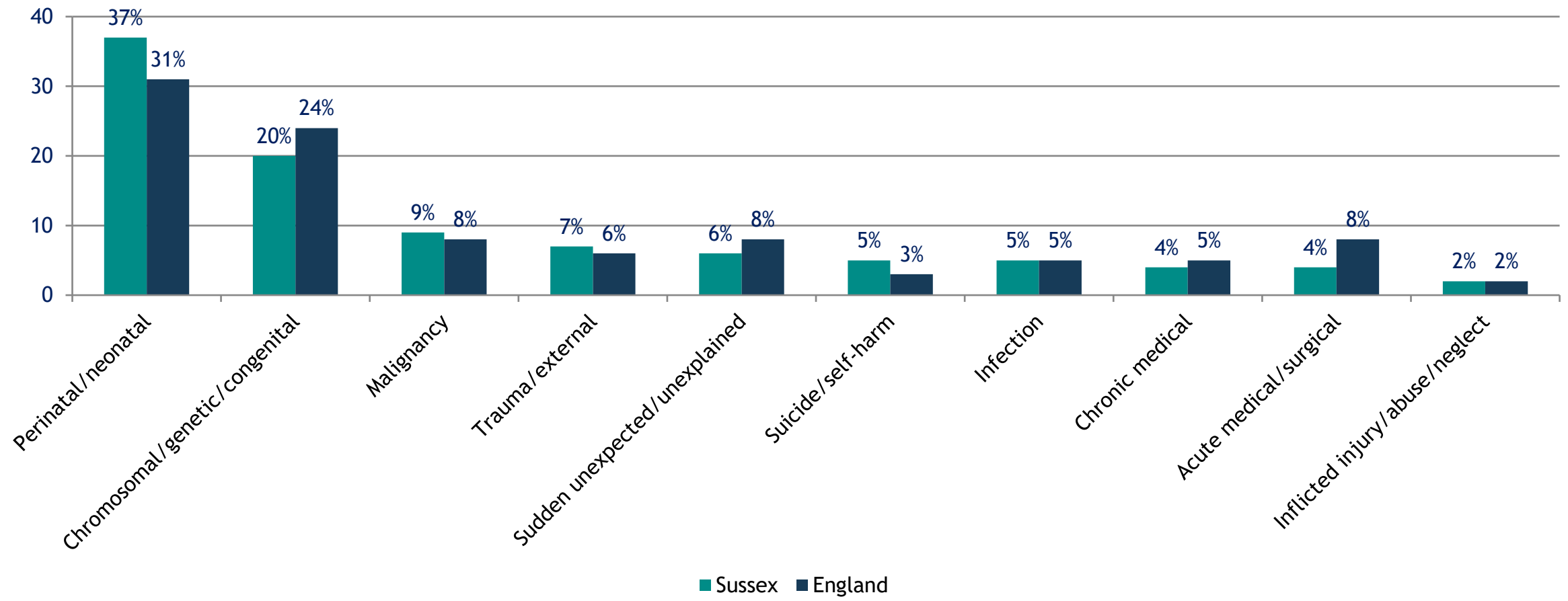


Equity requirement

CDOP identifies inconsistent access for families with limited English proficiency. Bereavement support should be culturally and linguistically appropriate.

Categories of child death

Completed Sussex reviews, pooled 2015/16-2024/25, compared with England reviews in 2023/24



Perinatal or neonatal events were the largest category, followed by congenital and genetic conditions.

Neonatal review and support for bereaved families

Learning from specialist review and the wider child death review pathway

Neonatal reviews

37 of 85 completed reviews, 44%, were undertaken by the neonatal panel.

Maternity learning

Recommendations covered robust telephone triage, training for intubation in pregnancy and documented informed decisions about induction.

Named keyworker

All 68 bereaved families were offered a named child death keyworker; in 35% of cases this was a Sussex CDR nurse.

Family support is integral to review

Keyworkers help families understand and navigate investigations, receive compassionate support and connect with appropriate services. The report notes strengthened collaboration with GPs, hospices, voluntary organisations and mental health providers.

Specialist neonatal scrutiny and consistent keyworker support are central to learning and family care.

Factors associated with child deaths

Findings highlighted through CDOP data and case review

Deprivation

Mortality rates were significantly higher in the most deprived areas of Brighton & Hove and East Sussex than in the least deprived areas.

Learning disability

Nine children aged 4-17 who died had a confirmed learning disability: 33% of deaths in this age group.

Modifiable factors

14 of the 85 deaths reviewed, 16%, had factors that could potentially be changed through achievable action.

Unsafe sleep and SUDI

Unsafe sleeping, disrupted routines, overcrowding, financial hardship, inadequate heating and mould were identified as relevant concerns.

Safeguarding

Themes included substance misuse, domestic abuse, school non-attendance and missed medical appointments for vulnerable children.

Clinical and system factors

Information transfer, joined-up working, asthma control, maternity triage and neonatal clinical practice featured in recommendations.

Risk and learning span social conditions, safeguarding, clinical care and the coordination of services.

Conclusion: need, unmet need, variation and future demand

Sussex has strong assets, but the current model relies heavily on local capacity and commitment

Need

Long-term, multidisciplinary support across health, hospice, social care, education, psychological care, respite and bereavement.

Unmet need

Dependable 24/7 support, community response, smoother transitions, earlier referral and coherent family support.

Variation

Geography, service criteria, workforce capacity, referral routes and access to specialist advice shape experience.

Inequalities

Deprivation, ethnicity, disability, language and ability to navigate services require active attention.

Future demand

More children are living longer with complex conditions and reaching transition age, increasing the duration and complexity of support.

System opportunity

Build a distinct pan-Sussex BCYP programme around existing hospice, CDOP, community and specialist expertise.

The direction of travel is earlier, family-centred, co-ordinated and equitable care, available whenever it is needed.

BCYP palliative and end of life care - recommendations

Recommendations consolidated into five system priorities for Sussex

1

A-C

PLAN BCYP AS A DISTINCT POPULATION

Recognise BCYP within strategic planning; build population intelligence; model demand, capacity and workforce; and reduce inequalities in access.

2

D-F

PROVIDE INTEGRATED, 24/7 COMMUNITY CARE

Create a Sussex-wide community model with equitable urgent support, specialist advice, a named medical lead and a key worker for every child.

3

G-H

IDENTIFY EARLY, PLAN AHEAD AND SHARE

Strengthen early identification and parallel planning, with consistent advance care, emergency healthcare and ReSPECT plans shared across settings.

4

I-K

BUILD A SUSTAINABLE, SKILLED SYSTEM

Define universal, core and specialist workforce roles; provide targeted training and specialist support; and ensure timely access to medicines and pharmacy advice.

5

L-O

SUPPORT FAMILIES, COMMUNITIES AND LEARNING

Coordinate family and bereavement support; improve accessible information and death literacy; and embed BCYP indicators in quality improvement and system learning.

From findings to delivery

Four practical questions for commissioners, providers and partnerships

Are children identified early enough?

Use diagnosis, deterioration and repeated acute contact to trigger specialist review and planning.

Can families get help at any time?

Specify 24/7 advice, urgent community response and clear escalation routes.

Does information follow the child?

Maintain one current, visible plan across tertiary, acute, hospice, community, ambulance and social care.

Is access equitable?

Track referral, service use and experience by geography, deprivation, ethnicity, disability and language.

Use CDOP, further develop hospice activity and data set, EoL dashboard data and family/workforce insight together to monitor progress.

What's next?

